

READY TO GIVE UP ON LIFE

THE LIVED EXPERIENCE OF OLDER PEOPLE WHO CONSIDER THEIR LIVES TO BE COMPLETED AND NO LONGER WORTH LIVING

Dr. Els van Wijngaarden MDMD Annual Lecture, 6th May 2017, London







WORLD DYING DUTCH: EUTHANASIA SPREADS ACROSS EUROPE

BY WINSTON ROSS ON 2/12/15 AT 7:46 AM



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Tod wird als freund erkannt, Käthe Kollwitz



Research aims

 To develop in-depth understanding of the phenomenon 'life is completed and no longer worth living',

as lived and experienced by older people (70+) in the context of the Dutch debate on 'elderly and the self-chosen death.

 To explore what it means to live in-between intending to end one's life at a self-directed moment and actually performing a self-directed death (or not).



Methods

- Phenomenological qualitative interview study
- 25 elderly people (70+)

- ✓ mean age: 82
- ✓ 14 women / 11 man
- ✓ different ideological and demographic backgrounds
- ✓ relatively healthy; no medical ground for euthanasia
- ✓ 15 participants suffered from (an accumulation) of age-related complaints



Results ~ **DISCONNECTION**

A tangle of inability and unwillingness to connect to one's actual life

- 1. a sense of aching loneliness;
- 2. the pain of not mattering;
- 3. the inability to express one's identity;
- 4. multidimensional tiredness;
- 5. a sense of aversion towards feared dependence.

Wijngaarden, E.J. van, Leget, C.J.W., Goossensen, A. (2015). **Ready to give up on life:** the lived experience of elderly people who feel life is accomplished and no longer worth living, Social Science and Medicine, <u>doi:10.1016/j.socscimed.2015.05.015</u>, (open access).



1. a sense of aching loneliness

- a lack of valuable relations and companionship
- distance from others
- a lack of reciprocity and support
- a "hindrance" to their children

My children are all managing on their own. Nobody lives a shabby life, thank God. But you know, they don't need me anymore. I know I'm not supposed to say it out loud, but if I visited my kids, I think they would say: "God damn, it's the old man again." (...) I'm just getting in their way(i_10).



2. the pain of not mattering

- no valuable contribution
- not taken seriously
- not needed
- rejected

It's just that, ... I cannot utilize my talents. I'm a techie, that's what I like to do. (...) So yes, I feel that I have a lot of experience and knowledge in that area, but society doesn't need me anymore. At the moment I strongly feel: my life is of no consequence anymore... (i_11).



3. a growing inability to express one's identity

- loss of identifying projects and activities
- loss of commitment
- loss of the self

If only I could express myself! I could give lectures, I could do lots of things, but I just sit here. Being unnecessary. Well, then it is easy to develop a desire for death. I just sit here in my own silence, it's very quiet.

Many days go by that I don't hear my own voice. This voice, my voice, which so strongly wants to talk... Well that's very difficult. I love people but I'm just sitting here all alone. (i_9)



4. multidimensional feelings of tiredness

- existential tiredness: fed up with life as-it-is
- existential boredom: listlessness
- mental tiredness: struggling with emotional grief
- physical tiredness: struggling with decline

"...if I only have to lift an arm to get something done, I already feel completely overworked" (i_4).



5. a sense of aversion towards feared dependence

- losing control
- taking away bodily and personal capabilities
- feelings of shame associated with lived or feared deterioration

I went out with Anita, watching birds, and uh, I said: "Oh, I need to pee", so I walked out of the bird hide, stood there and then I peed. But then, I'll just say it, I suddenly pooped too. Then I deeply, deeply cried, standing there outside in nature. I became intensely sad. (...) I do not know, I burst into tears, I felt so sad about this happening to me. (...) Yes, it was, so I think, I had no control at all, it just happened without my involvement... I stood there and it just happened unintentionally, it just happened...(i_23).



Summary

A tangle of inability and unwillingness to connect to one's actual life

An on-going dialectic tension between is and ought

- a desire to matter and the pain of feeling marginalized;
- a longing for connectedness and the pain of feeling disconnected;
- a desire for independence while facing increasing dependence/vulnerability.
- A yearning desire to end this process
 - ideating on manners to escape from uncomfortable feelings
 - death seems the only possible way out.



Narrative foreclosure

Life is not over, but one's life story is considered so

- a firm but vain attempt to resist an inevitably growing dependence
- unable or/and unwilling to identify with life-as-it-is: life is too alienated, too meaningless, too shameful or frightening
- being pro-active, independent people, the resistance is strengthened by a set of beliefs and by character.



Second research aim

To explore what it means to live in-between intending to end one's life at a self-directed moment and actually performing a self-directed death (or not).



Results ~ LIVING IN A SPLITS POSITION

Caught between intending and doing

People felt torn between:

- detachment and attachment
- rational and non-rational considerations
- urgency and postponement
- taking control and lingering uncertainty
- resisting interference and longing for support

Wijngaarden, E.J. van, Leget, C.J.W., Goossensen, A. (2016). <u>Caught between intending and doing</u>: older people ideating on a self-chosen death, BMJ Open (open access).

Wijngaarden, E.J. van, Leget, C.J.W., Goossensen, A. (2015). <u>Till death do us part</u>: the lived experience of an elderly couple who chose to end their lives by spousal self- euthanasia, The Gerontologist (open access).



Recent developments

- 2010: civil initiative 'Of Free Will'
- 2014: the Dutch Government established a 'Committee of Wise People'
- February 2016; presentation advisory report
- October 2016; reaction and proposal to legalize assisted dying for older people
- December 2016; a draft bill by the Dutch liberal party Democrats 66
- First months of 2017: fierce debate during election campaigns





Reflections on recent developments

This specific wish to die

- is a considerable existential challenge permeated with ambiguities and ambivalences (rather than a rational decision).
- has distinct social and positional dimensions.

Wijngaarden, E.J. van, Goossensen, A., Leget, C.J.W. (2017) **The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living**, The European Journal of Social Policy

Wijngaarden, E.J., Klink, A., Leget, C.J.W., The, B.A.M. (2017) Assisted dying for healthy elderly people in The Netherlands: a call for prudence (forthcoming).



Reflections on recent developments

Call for prudence

It is highly complicated - if not impossible - to establish

- 1. whether the wish to die is truly consistent over time.
- 2. whether the wish to die is without any external pressure.
- 3. whether the non-medical suffering is insoluble.
- 4. whether enabling an assisted death correctly addresses the (partly social) needs and concerns in the lives of these older people.

Besides, it might increase social pressure on other elderly people and reinforce stigmas about old age.

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Comments & discussion



Research logo_Completed Life

This logo is designed especially for this research project, based on the symbolism of the circle. The sketchily drawn lines refer to the process by which people give meaning to experiences and life. Designed by: <u>www.toomanywords.nl</u>



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